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Moving beyond project specific patient and public involvement in research

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KEY MESSAGES

- Patient and public involvement (PPI) in research is predominantly focused at the level of individual research studies; however, a move toward PPI being embedded within the wider infrastructure of the organisation may maximise benefits for all involved.
- This approach has potential to promote relationship building, generate more sustainable, efficient PPI practices and accelerate development of skills and expertise for patient partners, researchers and other stakeholder collaborators.
- Organisational level PPI requires adequate resourcing, co-ordination and cultural change.

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Contributors and sources

Dr Turner, Dr Aiyegbusi and Prof Calvert are members of the Centre for Patient Reported Outcomes Research (CPROR) at the University of Birmingham. The Centre has benefitted from involvement of patient partners at an organisational level and employs a number of strategies to embed PPI within the Centre's infrastructure and through external collaborations. The authors have previously presented this organisational approach to PPI in research at the UK PROMs conference (Birmingham 2018) and were awarded the prize for "Best Patient and Public Involvement". The authors have reflected on their experiences in the context of wider literature during the development of this manuscript. Dr Magdalena Skrybant is the Patient and Public Involvement and Engagement Lead for NIHR Applied Research Collaboration West Midlands (ARC WM). Dr Skrybant has extensive experience in PPI and knowledge of the literature and latest guidance which has informed our discussion. Mr Price is a patient partner within CPROR and member of the CPROR executive board. His experiences of PPI at an organisational level within CPROR have been important to inform the context on the manuscript and he wrote a box on

reflections of his experiences. He co-authored this paper and has given his full permission to be named on it.

Contributorship statement

GT and OLA drafted the initial manuscript. All the authors reviewed, revised and approved the final manuscript. MC is the guarantor for this work.

Patient involvement

Patient partner, Gary Price, has significantly contributed to this paper and is a co-author. Mr Price has been actively involved in planning the content and structure of the manuscript, wrote a reflection of his PPI experiences (box 4) and has reviewed drafts of the manuscript. Dr Skrybant has a wealth of experience working with public contributors and has represented their voices during the planning and writing of the manuscript.

Competing interest statement

MC has received personal fees from PCORI, Astellas, Takeda, Glaukos, and Merck outside the submitted work.

OLA has received personal fees from Gilead Sciences outside the submitted work. The remaining authors have no potential conflicts of interest to declare.

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Moving beyond project specific patient and public involvement in research

Grace Turner and colleagues explore patient and public involvement (PPI) in research and argue that developing the infrastructure for involvement at an organisational level can maximise benefits for all involved.

Introduction

Patient and public involvement (PPI) is an active partnership between patients, the public and researchers in the research process.(1) Patients and the public offer unique insights from their lived experiences which cannot be substituted by expert knowledge from clinicians, researchers or other specialist stakeholders. These insights are important to ensure research is relevant and high quality.(2) Furthermore, the public have a right to be involved in research which may affect them and, often, is publicly funded.(3) The active partnership distinguishes involvement activities from patient and public engagement which is the sharing of research, such as science festivals or newsletter articles, and people as 'subjects' or participants in research.(1)

There has been an international drive to promote and raise the profile of PPI in research and for PPI to change how research is designed and conducted.(4, 5) Recently, an international network for PPI in health and social care research was established which aims to promote and advance PPI through a global partnership.(6) Major funders of healthcare research increasingly expect evidence of comprehensive, meaningful PPI in the development of grant applications and planned PPI within the proposed project.(4, 5) For example, in the United Kingdom, the National Institute for Health Research (NIHR) have PPI policies within their research and grant committees and fund INVOLVE, a national advisory group to advance PPI.(4, 7) Similarly, in the United States, the Patient Centred Outcomes Research Institute (PCORI) promotes patient input to guide research questions and supports active involvement from patients in reviewing applications, sitting on advisory committees and providing feedback on policy documents.(5) Funder requirements and expectations have been important drivers for the increase in number of research studies involving patient partners in the planning and delivery of research.(2)

Research strategy and infrastructure

Currently, PPI in research is predominantly focused on specific aspects of individual research studies such as the initial study set-up, data analysis, report writing and dissemination.(8) Although major funders integrate PPI within their broader infrastructure, PPI within organisations, such as academic research centres, is often *ad hoc* with different projects conducting PPI independently from each other.(9) This 'siloe'd' approach has been identified as a barrier to effective PPI and resulted in a call for more collaborative practices.(9) An alternative method is for organisations to take a broader perspective whereby PPI moves beyond project specific activities and is embedded within the wider infrastructure of the organisation. Research organisations should have a public involvement strategy at an organisational level, which patient and the public contribute to and regularly review. To ensure patient priorities, perspectives and unique skillsets are incorporated within the organisational research strategy, public contributors could be included on strategy groups or executive committees and contribute to research prioritisation and major infrastructure bids. (Box 1). The latest NIHR INVOLVE Standards for Involvement includes indicators for organisations as well as individuals and organisations.(10)

BOX 1: Embedding PPI in an academic research centre

- The Centre for Patient Reported Outcomes Research (CPROR) is a world-leading centre for Patient Reported Outcomes (PRO) research. PROs capture the patients' perspective; therefore, it is essential to have the patients' voice at the heart of all our research activities.
- Patients and members of the public have been involved from the start through contributing to Centre Strategy and actively participating in the Centre launch.
- Patient/public partners are part of the research team and receive training and support and participate in activities in line with academic staff including inductions (tailored appropriately); assessment of training needs; representation on relevant management groups; attending events (such as conferences); participation in all activities from research strategy to dissemination; and inclusion in social activities, such as Christmas meals.
- We have integrated PPI within the CPROR infrastructure through a variety of different approaches, including: representatives on the Executive Committee; User Advisory Groups for individual research projects; co-production of training materials; co-hosting a 'Patients Included' accredited conference (Box 2); and collaboration with PPI experts from NIHR infrastructure to share knowledge and best practice.
- We promote capacity building through our online training resource PROLearn, which includes a free online module for patient advocates involved in the co-design of PROs research/reviewing research protocols. PROLearn was co-produced with patient partners.
(<https://www.birmingham.ac.uk/Prolearn>)
- We embed PPI within the Centre's research throughout the research cycle from research prioritisation and identifying new research topics, to dissemination including co-authored publications.

BOX 2: Patients included accredited conference

- **What we did:** Public contributors were at the heart of planning and delivering the UK and Ireland PROMS 2018 Conference (Birmingham, UK), which received the Patients Included Chatermark accreditation.
- **Public Involvement in planning the event:** The Conference Organising Committee included a public contributor and a PPI Lead who were involved in planning and delivering the event. Members of the public were involved in reviewing abstracts.
- **Public Involvement at the event:** 10 bursaries were offered for patients and the public. Public contributors who attended were supported by the PPI lead prior to the event, and received information on what to expect on the day, had catering to specific needs and could visit a dedicated stand on the day for all delegates where people could ask questions/receive information.
- **Impact of public involvement:**
 - Patient conference co-chair and presentations from public contributors ensured that priorities of patients were a focus for the day.
 - Panel discussions included perspectives from patients on the relevance of research areas, impact of research to improve health outcomes and future directions for research.
 - Public perspectives were included in decisions to award prizes including a prize for the best innovation in public involvement in PROMs research.
 - Public contributors were involved in writing summaries of the Conference
 - Article in the Journal of Patient Reported Outcomes
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6297120/>
 - Blog for the BMJ opinion
<https://blogs.bmj.com/bmj/2018/08/23/richard-lehman-and-magdalena-skrybant-a-day-at-the-proms/>
 - Successful inclusion of public contributors has ensured that future PROMs Conferences will involve public contributors in planning/delivering the event.

Benefits of an organisational level approach

Embedding PPI at an organisational level facilitates opportunities for shared learning across different projects and accelerated skill development, for both patient partners and academic researchers. Developing connections with PPI experts, such as PPI leads, within the organisation and wider research infrastructures, enables direct access to advice and guidance, and facilitates sharing of best practice and knowledge, such as the latest guidance and standards. In turn, organisations may develop their own standards for PPI based on their growing experience and expertise which enhances the conduct of future PPI activities and creates continuity for long-term patient partners.

Relationships develop over time; therefore, organisational level approaches to PPI may facilitate building and sustaining relationships with patients and the public, which has been identified as a key enabler to meaningful PPI.⁽¹¹⁾ Models of PPI which incorporate relationship building have greater impact than one-off PPI activities.⁽²⁾ Furthermore, such an approach may offer unique, unanticipated opportunities for research collaboration and co-production (Box 3). Evidence shows involvement in research has benefits for patients and the public, including: giving people a purpose; gaining new knowledge about their condition(s); understanding more about research and the latest evidence; opportunities to use existing skills and develop new skills; building confidence; and opportunities to meet other people and gain additional support (Box 4).⁽³⁾

BOX 3: Thinking outside the box- innovative patient partner collaborations

Patient partner, Gary Price, is employed as an International Product Manager at the company ERIKS, which provides customised, automated and innovative engineering solutions for design, manufacturing and production processes. Through discussions with Gary it became apparent that there was a clear opportunity to learn from ERIKS and consider how cutting edge process management, condition monitoring and use of cloud based technology in an engineering setting could be applied to healthcare. MRC Proximity to Discovery funding was secured to facilitate research group members to visit ERIKS European Innovation Centre in Rotterdam, fostering multidisciplinary collaboration, sharing of good practice and directly informing our research.



Group pictures taken after a tour of the ERIKS manufacturing plant to see first-hand the processes discussed earlier.

Picture 1, Left to right are: Wouter Siepman (Formerly ERIKS); Derek Kyte, Lee Aiyegbusi, Mel Calvert (CPROR members); Gary Price (ERIKS staff and CPROR patient partner)

Picture 2, Left to right are: Wouter Siepman (Formerly ERIKS); Mel Calvert, Lee Aiyegbusi, Derek Kyte (CPROR members)

(Permissions were granted by all for the pictures to be taken and used in subsequent publications. The pictures were uploaded to and are currently in public domain on the Twitter website.)

BOX 4: Experience of PPI from CPROR patient partner Gary Price

“Due to my profession as an engineer, I engaged in using patient reported outcomes when I was diagnosed with serious illness. As it was going to be a long process of intense treatment and (hopefully) recovery, I decided to create my own list of outcomes for physical, mental and wellbeing, then monitor myself to see how the drugs were affecting me long term. Each day I would rate myself adding in my blood test results along the way. I would send these to the clinicians every few days.

At first the team of clinicians that were treating me would have a bit of a laugh with me about my charts and graphs, but within a few weeks based on my outcomes they were using my results to discuss with me how to continue the treatment. This in turn meant they could see from a patient’s point of view and feeling, exactly what was going on, there were no surprises, no reason to see me for the sake of seeing me and more importantly I could continue receiving the high doses of drugs that saved my life.

Two years after my recovery, based on my recent illness experience and how I had dealt with it, the consultant who treated me asked if I would consider contributing to PPI for a cancer trial. Through this I met Prof Calvert who was developing a proposal for a new research centre for patient reported outcomes research and I was invited to contribute to the centre strategy. After initial meetings and understanding of what this involved and how it will help patients and clinicians in future, I gladly accepted the role and have been involved in the centre ever since. Four years on and I consider myself very fortunate to be a key part of a team that has the patient at the core of its strategy. I have been able to see how more and more health sectors that the CPROR engage with are realising the advantage of having a formal and structured PPI, introducing a new dynamic to how patients are viewed and treated. I have been able to see at root level how patients are involved from concept of trials to delivery and how the clinicians value their input.

Finally: There are other advantages that sometimes can help play a part with PPI. Take the case of myself, as part of my day to day job I have gained a lot of experience within condition monitoring and asset management industry. From this I have been able to channel a lot of my knowledge into helping and contributing to the research that the CPROR is doing on remote monitoring, data collection and analysis. I believe I am a good example of PPI where a patient not only has experience of a serious illness but also has experience of the work that the team is doing.”

Gary Price, CPROR patient partner

Challenges and facilitators

Embedding PPI in organisations is resource intensive and requires adequate funding, planning and time allocation (Box 5). Public contributors need to be supported in their involvement and should receive relevant training and reimbursement for their expenses and time commitment. Expenses directly incurred as a result of participating in research should be covered for clinicians and other collaborators and refreshments provided as required. Consideration should also be given to communication with public contributors, collection and sharing of feedback on public involvement, and evaluation and reporting of activities. Individual research projects should be appropriately costed for PPI training and activities.(12, 13) However, a challenge is the lack of funding opportunities for organisational level PPI, which is not associated with a specific research project, particularly in University settings.

In the past, clinical research was often based on research objectives and agendas of clinicians and researchers. The studies were mostly designed, conducted and disseminated by clinicians and researchers with little or no input from patients or the general public.(2) One of the issues with this traditional approach was that such objectives and outcomes may not match those prioritised highly by patients who are supposed to benefit from research studies thus potentially limiting the usefulness and impact of research findings.(2) PPI provides the opportunity for patients, their families, carers and the general public to become co-members of the research team, participate and contribute to research alongside clinicians and researchers. Widening involvement in research this way, particularly to include under-represented voices from minority and hard to reach communities, is a well-recognised challenge.(2) Embedding PPI at an organisational level has potential to accentuate a lack of diversity as the nature of organisation level activities may unintentionally create bias in recruitment of patient partners. For example, attending an organisation's executive committee meeting may not be possible for public contributors with work/ carer responsibilities and individuals from low socioeconomic backgrounds may find these meetings intimidating. Therefore, it is important that organisations are aware of these risks and take steps to actively address diversity. These may involve: developing relationships with local communities; widely

advertising involvement opportunities; provision of additional training and support for public contributors; and ensuring chairs of meetings have the skills to involve public contributors in discussions and decision making.(10) In addition, it is important to have varied, flexible opportunities for involvement (beyond formal meeting) and ability to adapt to people's changing circumstances and changes how much they want to contribute.

Although the proposed embedded model of PPI suggests all team members are actively engaged in PPI, having a person(s) who co-ordinates and is responsible for PPI can be beneficial to drive PPI initiatives, maintain momentum, monitor involvement strategies and outcomes, and be a named point of contact.(2) However, there is a danger that research teams become reliant on the PPI lead which may hinder team engagement with PPI and shared learning.(2) Ongoing, regular communication with public contributors, both formal and informal contact, is critical for building and sustaining relationships.(12)

Support from senior leadership is important to promote a culture of PPI as standard practice and to ensure organisations have a public involvement strategy. Cultural changes are required to embed PPI at an organisational level and to create an environment where PPI is valued by researchers and viewed as the norm rather than an added extra.(9) Involving patient partners in research should be done instinctively by all team members and patient partners should be regarded as integral members of the research team (Box 1).

BOX 5: Tips for successful partnerships

Changing culture

- Team effort – advocacy throughout institution from student and early career researcher groups to senior management committees
- Recognition for staff who lead/ facilitate public involvement activities
- Acknowledgement of patient partners are team members
- Involve patient partners in all team activities including social events
- Arrange an induction for patient partners (similar to a new member of staff)
- Demonstrate input is valued (honoraria, thanking people, listening and responding to ideas)

Practical considerations

- Accessibility and travel
- Reimbursement
- Training and support for patients, public and researchers
- Flexible working arrangements
- Develop processes to pay honoraria
- Have named contact for public contributors

Communication

- Explain the context of the research, such as rationale, timelines and relevance to clinical care and patient
- Listen to views and make necessary changes
- Establish roles and ground-rules
- Manage expectations
- Address any concerns
- Maintain regular contact
- Identify optimal mode/preferences/frequency of communication

Measure impact

- Consider use of key performance indicators – for example involvement of patients and the public on committees, grant applications, publications
- Use guidance for reporting patient and public involvement version 2 (GRIPP2) as a framework to report PPI. The checklist was developed in order to address inconsistent reporting by assisting researchers, patients, carers, and the public with the reporting of PPI activities so as to improve the quality, consistency, and transparency of reports.

Measuring the impact of PPI

PPI has the potential to positively impact on research at multiple levels, promoting quality and relevance of research and benefitting the wider research system.(11) Impact should be assessed by measuring pre-determined key performance indicators linked to research outcomes and processes(14) through qualitative and/or quantitative methods.(3) Individual level performance indicators could include acquisition of new skills and knowledge for the PPI contributors and better understanding of the research field from a patient perspective for the research team.(11) Research quality indicators could include PPI in research prioritisation;(15) contributions to research design and methods;(16) collaborations on grant applications;(17, 18) and dissemination of findings via co-authorship on publications and presentations at conferences.(3) Wider research system impact could be measured by assessing influence on advocacy and accountability in terms of the allocation of research resources.(14)

There is drive to capture key performance indicators for individual research projects; however, it is also important to document these indicators at an organisational level and think beyond project-specific objectives. The use of the GRIPP2 checklist(13) to report PPI activities and utilisation of the newly developed Cost and Consequences Framework(19) may enhance transparency and accuracy in the reporting of positive and negative impacts. Furthermore, consideration should be given to capturing 'soft' outcomes, such as relationship building, which are often more difficult to measure.

Conclusion

There is a need to move away from patients and the public only being involved in individual research projects and move towards models where PPI is considered at an organisational level and patient partners are valued team members. This approach has potential to promote relationship building, generate more sustainable, efficient PPI practices and accelerate development of skills and expertise for patient partners, researchers and other stakeholder collaborators. However, it requires adequate resourcing, co-ordination and cultural change.

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